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ABSTRACT

The monograph outlines key issues in the area of patients' rights and advocacy as they relate to Hispanic mental health clients or patients. Providing background material on patients' rights and advocacy in general, the first section includes a chronological history of major litigation, a discussion of patient advocacy, a discussion of a client's right to refuse treatment, and a legal perspective of patients' rights and advocacy. Focusing on patients' rights and advocacy for Mexican Americans in Texas, the second section includes a statement from the Commissioner of the Texas Department of Mental Health and Mental Retardation regarding systemic concerns and a discussion of the citizen's or consumer's point of view. A 1981 workshop on Hispanic patients' rights and advocacy is summarized. Interviews with 15 Hispanic therapists in Texas provide a perspective of the Mexican American service provider regarding the patients' rights movement's impact on Mexican American clients and identify issues arising from the uniqueness of the Mexican American experience in treatment. The concluding article delineates several assumptions predominating in mental health service delivery systems and in the patients' rights and advocacy movement that may be limiting the development of an Hispanic initiative. Appendices include academic and litigation references on patients' rights and advocacy. (Author/NQA)

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LITIGATION AWARENESS ADVOCACY

CUALES SON SUS DERECHOS?

THE RIGHT TO TREATMENT

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Patients' Rights and Advocacy: For Hispanics?

Sally J. Andrade, Editor



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MENTAL HEALTH RESEARCH PROJECT OF THE INTERCULTURAL DEVELOPMENT RESEARCH ASSOCIATION

The Intercultural Development Research Association's Mental Health Research Project (MHRP), funded by the National Institute of Mental Health, seeks to improve mental health delivery systems for Mexican Americans in the state of Texas.

The MHRP's major goals include: 1) a preliminary analysis of the effectiveness of the state mental health service delivery system and subsystems in providing services to Mexican Americans; 2) an assessment of the community mental health center concept as it relates to the Mexican American population; 3) the design of a bilingual/multicultural human service delivery model relevant to the mental health needs of Mexican Americans in Texas; and 4) the development of policy and programmatic alternatives to enhance the utilization of the state mental health service delivery system by Mexican Americans.

The MHRP has established a Texas Advisory Committee which consists of mental health service deliverers, professionals/academicians and consumer representatives from the five major geographical regions of Texas. The committee members serve as conduits for information dissemination and collection. To ensure maximum generalizability of the process and products of the MHRP, six nationally recognized professionals in the area of mental health and service delivery systems serve as consultants to the MHRP in the form of a National Advisory Committee.

The goal of the IDRA Mental Health Research Project is improved services for Mexican Americans in the state of Texas. Because a lack of agreement has existed in Census surveys and social science research as to the definition of a "Mexican American," potential problems emerge in attempting to compare data sources across regions or time frames. Terms encountered historically to identify this ethnic group include: Mexicans,

Mexican Americans, Spanish-surnamed, Spanish-speaking, Latin Americans, Spanish Americans, Hispanics, etc. The term "Mexican Americans" is used consistently by the Mental Health Research Project to refer to this population, indicating those residents who are of Mexican origin or descent. References to specific data sources may at times utilize the exact label cited therein (e.g., "Spanish Americans"); it is assumed by the project that the overwhelming majority of any such individuals in Texas are of Mexican origin.

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ABSTRACT

The monograph outlines key issues in the area of patients' rights and advocacy as they relate to Hispanic mental health clients or patients. The first section provides background material on the general topic of patients' rights and advocacy. Included are a chronological history of major litigation, a discussion of patient advocacy, the question of a client's right to refuse treatment, and the perspective of a lawyer.

The second section focuses on the state of Texas as a source of more specific information relating to patients' rights and advocacy for Mexican Americans. A statement from the Commissioner of the Texas Department of Mental Health and Mental Retardation presents systemic concerns, and the Mental Health Association of Texas discusses the citizen's or consumer's point of view. A summary of a 1981 conference workshop on Hispanic Patients' Rights and Advocacy is also presented. Interviews with Hispanic therapists in the state about patients' rights are described and analyzed by the IDRA Mental Health Research Project.

The concluding article delineates several assumptions which predominate in mental health service delivery systems and in the patients' rights and advocacy movement that may be limiting the development of an Hispanic initiative.

Appendices include academic and litigation references for the field of patients' rights and advocacy.



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FOR EWORD

The IDRA Mental Health Research Project (MHRP) wishes to express its appreciation to the National institute of Mental Health (NIMH) for the support of this initial effort at delineating the issue of patients! rights and advocacy from a Hispanic perspective. Tom Owan, A.C.S.W., Chief of Services for Minority Programs in the NIMH Division of Service Development, and Louis E. Kopolow, M.D., Chief of the NIMH Patients' Rights and Advocacy Section, initially conceptualized the idea of incorporating such a topic into the scope of the MHRP's research plan. Obviously, they cannot be held accountable for the content or quality of the document, for which IDRA, is solely responsible. But we are grateful that they challenged us to examine this issue and that they consistently supported us in our efforts.

The primary thrust of this publication is the need for a new conceptualization of patients' rights and advocacy. Because the topic of patients' rights has emerged fairly recently, indeed, because the concept of mental health is relatively new in the development of social services, the factors of race, ethnicity, culture and language have yet to be fully explored. The staff of the IDRA Mental Health Research Project were unable to identify mental health academic or service materials that focused on Hispanic patients' rights and advocacy, except in very general terms of arguments concerning the need for bilingual/bicultural services. The MHRP hopes that the monograph will stimulate more dialogue and scholarly attention to this topic.

We are indebted to all of the authors for their interest in helping to expand our understanding of what patients' rights and advocacy entails. We also want to thank Sharon Sepulveda-Hassell for her editorial assistance and Rosario H. Trejo for her consistently pleasant and professional support in producing this monograph.

David G. Ramirez
Principal Investigator
Mental Health Research Project
Intercultural Development Research Association

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NOTE TO THE READER CONCERNING REFERENCES

Because many of the authors tend to refer to the same basic references or legal cases, for your convenience, we have placed all citations into two appendices. The first appendix includes academic materials cited or other works recommended for additional reading on patients! rights and advocacy. The second appendix includes all legal cases and statutes referred to in the text. The one exception is the review of patients rights litigation written by Bowman, in which the case citations are included.

INTRODUCTION

Jose A. Cardenas, Ed.D. *

In 1977, Dr. Juan Ramos, Director of Special Mental Health Programs at the National Institute of Mental Health (NIMH), met with Dr. Blandina Cardenas Ramirez and me to discuss ways in which researchers working in the field of bilingual/bicultural education could dialogue more productively with service providers and researchers in the area of mental health. The concept of a research plan emerged out of that meeting, and subsequent NIMH funding led to the creation of the IDRA Mental Health Research Project (MHRP). In 1980, Dr. Louis Kopolow, Ghief of the Patients' Rights and Advocacy Section of NIMH, suggested to the Mental Health Research Project staff that they expand their research to include the issue of patients' rights and advocacy as it applies to Hispanic Americans. A small supplemental grant from NIMH permitted the MHRP to incorporate this important topic into its scope of work.

Patients' rights is a logical issue for IDRA to tackle. Though most of our activity has been in the area of education, we have extensive involvement in mental health because of our belief that the mental health status of the child and the family influences the learning environment and contributes to maximizing one's personal resources and potential. In addition to this advocacy, we have established a long-term goal to promote the collaborative interface of mental health/mental retardation services provided by community agencies and mental health/mental retardation support services provided by schools.

The rights of Hispanic mental health clients or patients, as can be seen in the articles of this monograph, have not previously been specifically identified or analyzed. To date,

^{*}Dr. Cardenas -is Executive Director of the Intercultural Development Research Association in San Antonio, Texas.



most service providers appear to believe that the vulnerability of an individual client lies in his or her unstable emotional state, mentally retarded condition or institutionalized status. There is little consciousness of linguistic or cultural issues that possibly affect the rights and entitlements of individuals in state hospitals or outreach programs, community mental health centers, drug or alcohol abuse programs, private therapy, or school counseling programs.

Therefore, the IDRA Mental Health Research Project is presenting this publication to focus the attention of its readers on the topic of patients' rights and advocacy. Our goal is to summarize relevant background information on patients' rights and to stimulate a greater awareness of the need for clarification of Hispanic mental health clients' rights as a function of their unique linguistic and/or cultural characteristics.

To our knowledge, this is a pioneering effort and, as such, entails all the excitement and limitations which characterize such an effort. We hope that it engenders a new commitment to advocacy for Hispanic mental health clients among our readers.



SECTION I

Background on Patients' Rights and Advocacy



1. THE EVOLUTION OF PATIENTS' RIGHTS

Mary B. Bowman, Ph.D.*

The United States is in a transitional period in the history One hundred years ago, with the help of of mental illness. Phillipe Pinel, health care professionals realized that the mentally ill remain human despite their ordeal. Fifty years ago, American legislation began a trend toward legislated guarantees. of humanitarianism for groups too legislatively weak to demand such considerations for themselves. Twenty years ago, guarantees of humanitarianism specific to the mentally ill began These guarantees are not yet resolved, for to be defined. various reasons, including the difficulty of developing a legislatively coherent understanding of the relationship between the mentally ill citizen and other citizens (e.g., the most typical problems of legislation have been the extent to which the state ought to exercize paternalism over the mentally ill). A review of several key cases will illustrate the current state of mental patients' rights and the types of problems that appear when an attempt is made to legislate the relationship between the state and the mentally ill.

Three fundamental concepts must be borne in mind as the reader studies the process of legislation of patients' rights. The first is the mechanism of legislation in this area. Rarely are changes made on the basis of legislation introduced through Congress or state legislatures. More often, they are the result of civil litigation -- resolutions of specific conflicts between specific parties. This means that the relevant law remains unchanged, but its specific application is defined. For instance, in Donaldson v. O'Connor, which will be discussed in more detail presently, the court was not asked to grant a right to liberty, but to interpret whether the law as it existed at that

^{*}Dr. Bowman is a Postdoctoral Fellow in the Mental Health Training Program at Rutgers and Princeton Universities in New Brunswick, New Jersey.



time implied a right to liberty for Donaldson, and thus, for certain people like him (non-dangerous mentally ill individuals). It is easy to see why ground gained through these channels will be gained slowly and will be less than revolutionary.

The second aspect of legislation affecting mental patients is that legislation typically has extremely limited generalizability between states. Any decision made by a state court sets precedent only in that state; most rulings on patients' rights are made at the state level. Consequently, patients' rights vary from state to state. It is quite common for a state court to choose to employ a ruling made in another state as a model. But there is no obligation to do so and there is no precedent between states unless the decision was made by a Federal Court.

The third aspect is the difference between a right and an entitlement. Rights are legislated for the population as a whole (human rights, e.g., the right to certain measures of freedom), or for a subset of the population, such as citizens (civil rights, e.g., the right to vote). Such rights cannot be abridged in the case of any individual without due process (e.g., a trial or a commitment proceeding). Entitlements, however, are those privileges extended by the state to any particular citizen. These also cannot be revoked without due process. There is no "right" to Social Security benefits. Yet a person may have entitlement to social security benefits extended to him or her under certain circumstances (e.g., having paid Social Security taxes for ten quarters and having reached the age of 62). civil disputes relevant to mental health legislation result not in the granting of a right (or the interpretation that such a right already exists) but in the granting of an entitlement. granting of an entitlement to an individual does not establish precedent as strictly as does the interpretation of a right, although class action suits resulting in entitlement rulings often are used widely afterward.



These aspects of the law clarify the reasons for widely divergent versions of "patients' rights" and the widely divergent, pinions about what each right actually entails. It is therefore virtually impossible to list nationally acknowledged patients' rights. Fore often, an accurate account reads more like, "State X adopts a <u>laissez faire</u> attitude toward the voting abilities of the mentally retarded on the basis of Smith having been granted an entitlement to an absentee ballot by State Y." In this rather typical account, the relationship between state and patient is unclear, precedent has not been set, and another state's model for entitlement has been accepted. Note that the statement does not say, "State X affirms the right of the mentally retarded to These are the sorts of difficulties characterizing legislation affecting the mentally handicapped. Several key cases of this legislation will demonstrate both the current status of patients' rights and the impact of the principles described above on those rights.

CIVIL COMMITMENT

This procedure is undertaken by the state, when justified either by the state's police power to protect the citizenry from emotional, mental, physical or financial harm resulting from the mental illness of another person, or by the state's obligation to assume parens patrie (paternalism) over an individual to protect him or her from self-inflicted harm or to provide him or her with what is needed when he or she is incapable of requesting it (e.g., treatment or custodial care). The wisdom and justifiability of both of these powers have been exhuberantly criticized.

The standard or conditions employed in justifying the exercise of either of these powers are two: danger to self or others due to mental illness, or need of care and treatment for mental illness. The ability to judge either of these conditions has been equally criticized.



Dooling v. Overholser, 243 F.2d 325 (D.C. Cir. 1957). It is unconstitutional to assume that because a patient has not actively demanded counsel, that individual is waiving his or her right to counsel. Further, a person subject to civil commitment cannot knowingly and intelligently waive a right to counsel. In effect, the patient must be provided with counsel, whether he or she requests it or not, in any commitment proceding.

People v. English, 201 N.E. 2d 455, 458 (III. 1964). This case established the right to confront all evidence in a commitment proceeding; hearsay evidence was ruled out. This was confirmed on the Federal level by Lessard v. Schmidt.

Baxtrom v. Herold, 383 U.S. 107 (1966).. The patient has a right to due process in all commitment procedings, including the right to notice, to a hearing, to be present, and to present a defense. (In Texas, this also includes the right to have the hearing decided by a jury.)

People ex rel Rogers v. Stanley, 17 NYS 2d 573 (1966). This case affirmed the right to habeas corpus (the right to obtain a writ against illegal imprisonment).

In re Gault, 387 U.S. 1 (1967). The adult patient does not have the juvenile's parens patrie right to a closed hearing. (In Texas, the judge may exclude anyone from the hearings whom he or she judges not to have a legitimate interest, but only with the patient's consent.)

In re Winship, 397 U.S. 358 (1970). The burden of proof in commitment hearings falls on the state.

Dixon v. Attorney General of Commonwealth of Pennsylvania, 325 F. Supp. 966 (M.D. Pa. 1971). A patient has the right to "independent expert examination and assistance in preparation for the hearing," and these services must be court appointed if the patient cannot pay for these services.



Lessard v. Schmidt, 349 F. Supp. 1078 (E.D. Wis. 1972). This case also affirmed the right of a patient to a courtappointed attorney in an involuntary commitment proceding.

RIGHT TO TREATMENT

There is considerable academic dispute over whether the "right to treatment" established by the courts is in fact a right to treatment and not merely a right to liberty if the patient is neither manifestly dangerous nor under a civil commitment for This is merely an academic dispute; the courts do observation. not refer to a right to treatment out of inarticulation. however, an entitlement to a class of people: those committed to a mental institution. The noncommitted population does not have a right to weekly psychotherapy for their angst. implication, however, is one of liberty; a commitment is invalidated if the patient does not receive treatment and is not manifestly dangerous. He or she may then leave the institution, beause not to allow the patient to leave would be ipso facto to deny that individual his or her right to treatment within the hospital.

Rouse v. Cameron, 373 F 2d 451 (1966). This was the first court recognition of the right to treatment. The court also established that the resolution of a patient's failure to receive treatment lay in habeas corpus, not in a "second chance" for the institution.

Nason v. Superintendent of Bridgewater State Hospital, 339 Mass. 313, 223 N.W. 2d 908 (1968). Nonpenal commitment without treatment violates the due process and equal protection clauses of the Constitution.

was a class action suit brought against the State of Alabama, in which it was held by the court that there is a clear constitutional right to treatment for both the mentally ill and



the mentally retarded (although the specific nature of treatment is different for the two groups). This was the first assertion of a right to treatment for the mentally retarded.

Tippett v. Maryland, 436 F 2d 1153 (4th Cir, 1971). Being "manifestly dangerous" does not negate the right to treatment, although in the case of a manifestly dangerous patient's failing to receive treatment, proper redress is not in release, as it is with the non-dangerous patient, but in the provision of treatment.

Donaldson v. O'Connor, Civil Action No. 1693 (M.D. Fla., 1972). Probably the most often cited (and most often mis-cited) of the right-to-treatment cases, Donaldson established that there is, as the judge in this case instructed the jury, a "Constitutional right to receive such individual treatment as will give him a realistic opportunity to be cured or to improve his or her mental condition." This is not merely a specific case of the right to liberty. The right to liberty establishes the proper redress to a failure to receive one's right to treatment (i.e., the patient is released; the hospital does not get a "second chance" to fulfill the patient's right to treatment).

This ruling only applies to those who are not manifestly dangerous, which means that it does not assert a right to treatment for the manifestly dangerous. This implies that the right to treatment follows from a parens patrie involuntary commitment, but not necessarily from a police power involuntary commitment. Also note that this was a civil action brought by Donaldson against a hospital superintendent and a staff psychiatrist at the hospital, and not against the state. It is a case of the most limited precedent, and yet has been accepted as a model in many counts.

Burnham v. Department of Public Health of the State of Georgia, 349 F. Supp. 1335 (N.D. Georgia, 1972). This federal court held that there was no constitutional right to treatment (although there is a moral right to treatment). The judge was primarily basing his opinion on the conviction that issues such as quality of treatment cannot be legislated, but also on an interesting interpretation of the Eleventh Amendment: that it precludes a federal mandate requiring state expenditures in an area controlled by state law.

Rozecki v. Gaughan, 459 F. 2d 6 (1st Cir. 1972). Confinement and failure to receive treatment offend the Eighth Amendment; the fact that confinement is hospitalization and not criminal in nature does not render the Eighth Amendment inapplicable. Such confinement can be challenged on the basis of being cruel and unusual punishment.

FIRST AMENDMENT RIGHTS (freedom of religion and thought)

Most other rulings relevant to the First Amendment rights of patients have been asserted on behalf of prisoners and presumed to generalize to mental patients. This generalization is widely accepted, but may be challenged. Nonetheless, because mental patients are generally thought to be entitled to an environment at least as habitable as that of prisoners, those cases are relevant.

Kaimowitz v. Michigan Dept. of Mental Health, 42 U.S.L. Week 2063 (Mich. Cir. Ct. Wayne City, 1973). The involuntarily committed patient is legally incapable of consenting to psychosurgery (note psychosurgery," rather than "neurosurgery," of which it is a class), and that regardless of any apparent consent, such surgery amounts to a violation of the patient's First Amendment "freedom to generate ideas", as well as the constitutional right to privacy (which may under other circumstances be abridged in the face of a demonstrated compelling state interest).



Cooper v. Pate, 378 U.S. 546 (1964). The entitlement of prisoners to gather for religious services, to consult members of their faith, to possess religious books, to subscribe to religious literature, to wear unobtrusive religious medals and other symbols, and to have a special diet as required by their religion was upheld. (It is easy to see how this rule might be difficult to interpret regarding mental patients; how private can one's beliefs be and still qualify as "religious"? The religious or psuedo-religious beliefs of mental patients are often the targets of therapy, especially when the therapist and the patient are of different racial or cultural backgrounds, and, therefore, may have very little understanding and tolerance for one another's religious beliefs.)

Lamont v. Postmaster General, 381 U.S. 301 (1965). Communication by mail is a constitutional right affirmed by the First Amendment, which cannot be abridged for criminal prisoners. The Texas Mental Health Code (Section 85) establishes the rights of patients, "to communicate with persons outside the hospital; and to communicate by uncensored and sealed mail with legal counsel, the Board, the courts and the Attorney General of the State." This implies that only communications of the second sort must be uncensored; all other communications may be censored.

Carothers v. Follette, 314 F. Supp. 1014 (S.D. N.Y. 1970). Prisoners cannot be punished for complaining to others about institutional conditions and treatment.

<u>Winters v. Miller</u>, 446 F 2d 65 (2d Cir. 1971). Mental patients (as well as inmates) have the right to refuse any nonemergency medical treatment on the grounds of their religious beliefs.

SIXTH AMENDMENT RIGHTS (the right to counsel)

These have been established for the mentally ill in the strongest of terms by the Federal Courts.



Seale v. Manson, 326 F. Supp. 1375 (D. Conn. 1971). The patient's right to access to counsel was affirmed.

Lessard v. Schmidt (supra). As discussed under civil commitment in this article, the patient's right to counsel, and to court-appointed counsel if need be, is firmly established.

FOURTH AMENDMENT RIGHTS (due process)

Many of these issues, being particularly relevant to the civil commitment process, have already been discussed. However, in addition, court rulings (again, primarily for prisoners) have established the bounds of Fourteenth Amendment rights in other cases.

Tally v. Stephen, 247 F. Supp. 686 (E.D. Ark. 1965). The ruling in this case required procedural safeguards of due process in the use of restraining straps as a disciplinary measure. Note that this was specific to the disciplinary use of such mechanisms; regulations other than due process apply to the use of such mechanisms for protection of the patient or other patients.

Jackson v. Bishop, 404 F 2d 571 (8th Cir. 1968). This ruling prohibited the use of the strap altogether because of the categorical inability to meet due process requirements.

<u>Williams v. Robinson</u>, 432 F 2d. 634 (D.C. Cir. 1970). Any transfer of a patient, either between institutions or to a maximum security section of the same institution, must be governed by due process safeguards.

Goldberg v. Kelly, 397 U.S. 254 (1970). The Supreme Court held that welfare payments could not be terminated without due process. The Texas Mental Health Code (Section 14.B) entitles the state to reimbursement by the patient or by his or her



guardian. (This routinely takes the form of practical confiscation of Social Security benefits. The practice may violate the Goldberg precedent requiring due process in such situations.)

THIRTEENTH AMENDMENT RIGHTS (prohibition of slavery)

justified variously Institutional peonage is "therapeutic" or as compensation for services provided. The former is at least theoretically justified by psychological thought on the matter - but not in the form of peonage, only as paid work. The latter is not so easily justified and has not been endorsed by the courts. The difficulty is that while the courts agree that peonage is unacceptable and that mentally handicapped persons must be compensated for work performed, the minimum wage is often inappropriate for the quality and quantity of work Therefore, some groups (including the mentally handicapped) are exempted from the entitlements to minimum wage as described in the Fair Labor Standards Act (29 U.S.C., Section 214) and may be employed for as little as 50 percent of the minimum wage, if the employer meets the criteria for such hiring each patient (the filing and approval of a certificate).

The right to compensation for work performed has been asserted through various measures, including private damage suits Treadway, Civil Action No. 6500 (D.C. Tenn. 1972)/; injunctive actions Souder v. Brennan, Civil Action No. 482-73 (DDC, 1973)/; Thirteenth Amendment suits (Dale v. State of New York); and suit for right to treatment (Wyatt v. Stickney, supra).

EIGHTH AMENDMENT RIGHTS

Protection against cruel and unusual punishment takes an interesting form in mental illness litigation. Since hospitalization, however involuntary, is not legally thought to be punishment, the cruelest of conditions only questionably



qualifies as "cruel and unusual punishment." Nonetheless, the Eighth Amendment has successfully been called upon to protect patients both from "cruel and unusual" (substandard) general conditions and from "cruel and unusual punishment" specifically (i.e., cruel disciplinary measures). But this has not been a direct victory for mental patients. The victories have been won by prison inmates and subsequently generalized to mental patients.

<u>Seclusion</u> has not been prohibited (except in Alabama as per <u>Wyatt</u>), although its use is often prohibited for punishment. Its use is tightly regulated for safety when used, for example, to protect other patients.

Experimentation and dangerous therapies have been addressed by institutional requirements for informed consent and other constraints on experimentation, as well as generally responsible state codes, in order to protect the patient from experimental hazard. The Eighth Amendment has not been successfully used to protect the patient from these practices, although in Mackey v. Procunier, 477 F 2d 877 (9th Cir. 1973), the Court did acknowledge that the Eighth Amendment would be an appropriate basis for litigation, especially regarding aversive and irreversible therapies.

The right to decent living conditions has been established as an Eighth Amendment issue with great specificity. Indeed, it cannot be asserted without specificity because of the ambiguity of the terms.

Sinclair v. Henderson, 331 F. Supp. 1123 (E.D. La. 1971). The Court agreed that protracted confinement without the opportunity for outdoor exercise "does, as a matter of law, constitute cruel and unusual punishment." This decision was directed at a prison system, but is accepted as clearly generalizable to the mental institution.



<u>Wyatt</u> (supra) was also able to enter the general living conditions of the defendant mental institution as substandard and therefore in violation of the Eighth Amendment.

The right to education is not absolute; no Federal Court has upheld a constitutional right to education per se, although handicapped children have the same entitlement to education as nonhandicapped children if the state offers it at all (which of course, all states do). The legislation concerning the entitlements of handicapped children to appropriate education had been inconclusive until Lau v. Nichols, 414 U.S. 563 (1964) established that the form of education must be appropriate to the child. Whether the Lau v. Nichols decision will be forcefully applied to, for example, the mentally retarded Spanish-speaking child in a state school has yet to be determined.

The right to least restrictive alternative setting for treatment was addressed in Shelton v. Tucker, 364 U.S. 479, 488 (1960). The court upheld the general principle that liberty is not to be revoked without due process, nor lightly. Therefore, the extent of any justifiable restriction of liberty must be only so great as to achieve the necessary ends. The Court declared that, "even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle personal liberties when the end can be more narrowly achieved."

Lake v. Cameron, 364 F 2d 657 (D.C. Cir. 1967). The courts may not simply choose to use their discretion as to whether the specific setting is appropriately nonrestrictive; they must actively pursue, explore, and compare settings. In other words, the court cannot simply assume the attitude that, "This setting is nonrestrictive enough", but must actively compare reasonable alternatives.



SUMMARY

The trend of litigation of patients' rights has been to establish that commitment to a mental hospital does not amount to sufficient due process for revoking civil and human rights beyond the abridgement of liberty. Court decisions have consistently established that mental patients retain such rights as freedom from peonage and the right to counsel. Furthermore, they have been granted specific entitlements, such as an entitlement to treatment. The present political focus on cost-effectiveness as the primary criteria of program effectiveness, however, makes it difficult to predict whether this humanitarian trend will continue.



2. ADVOCACY FOR THE MENTALLY ILL

Louis E. Kopolow, M.D.; Nancy C. Paschall, Ph.D.; Anita Eichler, M.A.; and Jerry Osterweil, Ph.D.*

Mentally ill persons have a special need for help in asserting their rights and procuring their entitlements. Mental illness at times makes it difficult for them to articulate their concerns and needs. The stigma associated with mental conditions often results in society's underestimating their capacities, placing a low priority on their demands, or even assuming that they do not have the same rights as others. Occasionally, a crisis leads to short-lived attention, but not to sustained support for the rights of the mentally ill. The complexity of mental health treatment and support systems often stymies their attempts to get needed help or protection from abuse.

Advocacy has the potential to change the rhetoric of patients' rights into reality. The term itself, however, has often been misunderstood, resulting in unnecessary disagreements and antagonisms among those who seek the same or complementary goals. This paper attempts to clarify the various forms that patient advocacy has taken. Beginning with an overview of the forces and events that led to the development of advocacy initiatives for the mentally ill, the remainder of the paper discusses why there continues to be a need for advocacy, the nature of advocacy, including the characteristics of effective advocates, and the functions of advocacy.

Background

Recognition of the critical need to represent and assist mental patients in dealing with abuses is what spawned the development of the patients' rights and advocacy movement. This

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movement has sought to protect basic human and civil rights, to end any patient abuse, and to create a more responsive mental health system. The initial focus of rights and advocacy was on large public institutions where patients were housed but often neglected or even mistreated. Patients' rights groups and civil liberties attorneys began bringing suits on such issues as the right to treatment, the right to the least restrictive alternative to hospitalization, and the right to liberty. In the late 1960s and 1970s, courts that had previously refused to rule on matters of medical treatment began to question whether conditions enabling treatment to occur actually existed in residential facilities to which mentally ill citizens were committed.

In recent years there has been a shift in attention from hospital to community-based care for mentally ill persons. Here, too, clients and their advocates have often found it necessary to battle for the basic protection, entitlements, and opportunities enjoyed by other citizens. The shift in attention to the community has been a result of the system's changes that brought about deinstitutionalization of mental patients. With this movement has come an unsettling discovery that many of the same problems that plagued individuals in the hospital followed them, upon discharge, into the community.

One reason that old problems of abuse have persisted in community settings is that comprehensive community support systems have not been sufficiently available to patients leaving the hospital nor to those without previous hospitalization. Without the physical or economic means, the motivation, or the understanding to search for needed help, many persons disabled by mental illness encountered problems that contributed to or precipitated a need for rehospitalization. Inadequate and unsafe community residential alternatives created similar problems and abuses. The most fundamental needs -- fresh and nutritious food, safety, cleanliness, space and adequate medical and psychiatric care -- often were not met.



Thus, the recent history of deinstitutionalization efforts has shown that the need for a strong patient advocacy movement does not stop at the door of institutions. The need not only persists but also has become increasingly complex, as patients must learn how to draw from a variety of community resources in order to remain in the community. Needed resources are not available in many communities; access to those in place may be difficult to obtain. In addition, problems of discrimination in housing, employment, and educational opportunities have become prominent.

Why There Is a Need

There are many reasons why advocates are necessary for current, former and potential clients of mental health services delivery systems. The first and most crucial factor is the vulnerability of mentally ill individuals. While many groups are neglected or underrepresented in their relationship to various institutions and organizations, the mentally ill as a group are the most underrepresented.

* In addition to the extreme vulnerability in which mental health recipients find themselves, they also suffer from special problems. The first of these is the handicap of the illness itself which makes it difficult for them to articulate their needs effectively. A second and greater problem is the stigma attached to being a consumer of mental health services. This stigma leads to society's tendency to prejudge the capacity ofmental health consumers and to underrate their ability to function outside a controlled environment and to make decisions for themselves. A third stigma-related problem is the tendency of mental health providers to interpret everything a client states or requests as being significant beyond the statement, e.g., requests for aspirin for a headache are interpreted as arising from a need for attention, requests to leave the facility are interpreted as resistance to treatment, etc. The fourth



stigma-related problem is the low priority given to a patient's concerns, simply because the individual is a patient. Far too often the wishes of mental health clients are denegrated, ignored or treated as the ramblings of children who do not really know what is good for them.

An additional special problem of the mentally ill patient is the difficulty of maneuvering through the incredibly complex support system which is created for the handicapped person but for which few road maps have been developed. In addition to the need for advocacy to deal with the vulnerability issues and special problems of the mentally ill individual, there is also a need for the change agent, monitoring force or watchdog to bring about the creation of more responsive mental health services in a system which historically has been conservative and slow-moving.

What Advocacy Is and Is Not

Advocacy means coming to the aid and speaking on behalf of another. It also conveys the idea of the promotion and support of a cause. Advocates who speak on behalf of another take their mandate from the expressed wishes of the client. They believe their primary role to be one of helping another person to obtain what he or she wants. The intention of this representational advocacy precludes the use of the advocate's idea of "what's best" for the client; instead, the advocate acts as agent for the client. In adhering to this principle of client self-determination, specific advocacy activity may vary dramatically, i.e., it may range from supporting the right to treatment to supporting the right to refuse treatment.

The other major direction in advocacy is adopted by those who base their efforts not only on the expressed desires of patients but also on their own knowledge and experience. They see their role as one of improving services for clients as well as protecting them. Such supportive advocacy is often practiced by:



- concerned citizens and groups, including action volunteers who draw on their volunteer experiences to promote legislative initiatives to improve care and public understanding of mentally ill persons;
- families and friends who utilize their experience of living with and caring for clients to define what reforms they believe are needed;
- mental health professionals whose training and experience enable them to advocate for high-quality care:
- lawyers who utilize their Legal training to seek administrative change through negotiation or litigation; and
- members of minority groups whose unique life experiences qualify them to speak for the needs of their particular groups.

Many advocacy activities aim to "empower" clients in situations where they have traditionally been powerless. The need for such activities arises from inequities: the system has often excluded mentally ill persons from decision-making about their own lives, ignored their rights, and denied them access to information and services. Beyond the task of assisting clients, however, lies the more advanced goal of enabling them to speak and act for themselves. Client empowerment is not intended to encourage power over someone else; instead, it implies an equitable distribution of power which recognizes the right and capability of people to exercise control over their own lives.

Client empowerment can mean either assisting clients to work in partnership with the professional caregiving system or enabling the implementation of alternative programs that are



separate from the professionally controlled system. Empowerment as partnership can take a number of forms, including increased client assertiveness on an individual base; use of self-help groups as an adjunct to therapy; and involvement in planning, governing, and monitoring services delivered by professionals. Empowerment can go beyond partnership with professionals to partial or complete alternatives to this service system. number of such client-controlled service settings do exist in The anti-psychiatry movement would this and other countries. hold that complete de-professionalization of required. Somewhat more moderate in their aspirations are the many patient and ex-patient organizations designed to promote both mutual aid and political activity. Some of these groups advocate significant departures from the professional service system; others support such a system.

The foregoing discussion has presented a number of advocacy activities, directions, and goals. It is equally important, however, to clarify what advocacy is not. Advocacy is not therapy, although it may have therapeutic consequences; e.g., strengthening a patient's self-determination and reducing a sense of helplessness. Although a therapist may act as an advocate when promoting legislative or administrative change to further the protection of rights or to improve mental health care, therapy itself is not advocacy. Nor does management of the mental health system constitute advocacy. Rather, the manager or administrator's role is to coordinate the organizational needs of the system.

How Advocate Function

A general functional typology of advocacy allows one to identify four functional strategies, including rights protection advocacy, legal advocacy, services advocacy, and systems advocacy.



Rights protection advocacy is performed by on-site persons who educate clients and staff concerning rights issues and who investigate complaints of rights violations. These advocates are usually employees of the facility or service system, but they may also be volunteers from various local or federal programs or persons paid from some other source, e.g., a Public Defender's Office. Such advocates should also be able to negotiate the system to allow early attention to grievances. If these efforts do not result in resolution of complaints in a manner acceptable to the client, the rights protection advocate needs to be able to refer the complaint either upward in the system or to another advocate outside the system, such as a legal advocate.

Legal advocacy is undertaken by attorneys, sometimes with the assistance of paraprofessionals. Legal advocates represent individual clients or classes of clients and have the authority to pursue formal legal remedies for them. When litigation is not used, the threat that this could occur can increase the advocate's bargaining power. Legal advocacy, however, cannot be characterized solely by the use of litigation. Lawyers or paraprofessionals also represent clients in administrative hearings and perform other functions such as lobbying, public education, and services advocacy.

Services advocacy refers to those functions performed to assist clients who reside primarily in the community and who are in need of various services or entitlements, e.g., Social Security benefits, rehabilitation or social services, but who encounter bureaucratic obstacles to obtaining such. This form of advocacy may be performed by volunteers, professionals, expatients and others.

Systems advocacy entails a large number of activities designed to bring about system-wide policy changes. Such changes may result from litigation, legislation, or administrative actions. Many types of persons engage in this form of advocacy,



including consumers, ex-patients, families, volunteers, service professionals, attorneys, legislators, and administrators. The means used vary and include strategies to capture public attention, such as confrontation, demonstration, and media events; class action litigation; lobbying for and writing legislative reform; formulating administrative regulations; and pressuring for reallocation of funds.

Summary

At this time, the field of advocacy for mental health clients is in flux. There is a sense of innovation and change in the face of litigation achievements, but there is also an awareness that societal goals seem to be shifting from an emphasis on civil rights and personal liberty to economic stability and public cost-containment. What kinds of future activities are required to ensure quality mental health services will depend to a great extent on the creativity and renewed energy of patient advocates.

The advocacy role will require courage in the face of opposition, persistence in dealing with obstructionism, and patience in working with suspicious clients and hostile staff. Working as a change agent with the long-term goal of creating more responsible mental health systems will generate periods of isolation and frustration for the individual advocate or advocacy group. But they can be sustained in their work by the knowledge that without their efforts, the concerns, fears and wishes of many patients would not be heard, attended to or resolved. The essence of advocacy on behalf of mental health clients is to affirm and defend that spark of humanity or "personhood" which exists in every client in spite of his or her status as patient.



3. THE RIGHT TO REFUSE TREATMENT

Deborah Cortez Hiser, J.D.*

In recent years, a great deal of attention has been focused on the rights of mental patients. Of particular importance to professionals engaged in the delivery of mental health services are recent judicial decisions holding that an involuntarily committed patient has a right to refuse certain types of treatment. This article endeavors to discuss the legal theories of the right to refuse treatment and their implementation in recent court decisions.

In the past years, the use of psychotropic medication has played an increasingly important role in the treatment of mental illness. Because restrictions on the administration of psychotropic medications pose the greatest potential problem for psychiatric professionals employed in state institutional facilities, this discussion will be limited to the right of a mental patient to refuse such treatment.

Legal Theories of the Right to Refuse Treatment

Currently, there are at least three legal theories under which mentally ill patients have asserted the right to refuse treatment. The first theory is medical malpractice based on violations of common law tort doctrines. A physician who subjects a patient to compulsory treatment may be held civilly liable for committing a battery. In tort law, a battery is defined as the intentional, unlawful application of force to the person of another. An injection of medication without the patient's permission, for example, may leave the physician open to liability.

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Civil liability may also attach under a negligence theory if the physician treats a patient without first obtaining his or her informed consent. The term negligence refers to conduct which falls below the standard established by law for the protection of others against unreasonable risk of harm. Informed consent is generally defined as consent given only after a full explanation to the patient of the nature and risks of a medical procedure. Accordingly, if a reasonably prudent physician would have so informed the patient before administering medication, a physician's failure to do so may subject her or him to civil liability for negligent malpractice.

The second theory under which patients have attempted to assert the right to refuse treatment is that the treatment state's statutory standards governing violates the commitments. It is of critical importance to recognize that each state has discretion, subject to state and federal constitutional requirements, to legislate the standards which will justify civil commitment. Consequently, a state court's interpretations of the state's commitment statute is not binding and provides no precedential value for patients residing in another jurisdiction. Additionally, standards for civil commitment vary according to the type of commitment at issue. Thus, a patient's success in asserting a right to refuse treatment may depend on whether she or he has entered the hospital voluntarily or whether the court has ordered that the patient be confined for a temporary or indefinite period.

One federal court has recently addressed the issue of whether a patient has a statutory right to refuse treatment. In A.E. and R.R. v. Mitchell, involuntarily committed patients were unsuccessful in seeking relief from compelled medication. Under the Utah commitment statute, commitment is permitted only if, inter alia, the court finds that the proposed patient "lacks the ability to engage in a rational decision-making process regarding the acceptance of medical treatment as demonstrated by evidence



of inability to weigh the possible costs and benefits of treatment." In <u>Mitchell</u>, the court held that no patient may be committed under the statute without a finding of incompetency to consent to proposed medication and that this suffices to establish incompetency when, after commitment, medication is administered over the patient's objection.

In contrast to the Utah commitment statute, the Texas Mental Health Code provides that a judicial determination that a person is mentally ill or the admission or commitment of a person to a mental hospital, without a finding that she or he is mentally incompetent, does not constitute a determination or adjudication of the mental competency of the person ...(Art. 5547-83(B), V.A.C.S., 1975). Notwithstanding this provision, the consent of an involuntarily committed patient has not been held by Texas courts to be a prerequisite to treatment.

The third and most significant theory under which proponents of the right to refuse treatment have challenged the use of compulsory psychotropic medication as a treatment modality is the Fourteenth Amendment right of privacy. In Rennie v. Klein, the court held that in the absence of a strong countervailing government interest, mentally ill persons in a state hospital have a constitutional right to refuse treatment in non-emergency circumstances. In the court's opinion, this right is founded on the constitutional right of privacy which encompasses both the protect one's mental processes from government interference and an individual!s autonomy over his or her own body which demands that a person subjected to the harsh side their effects of psychotropic drugs have control administration.

The court did, however, identify three factors to be considered if the state determined that it were necessary to override the patient's right to refuse treatment. First, the state's police power permits it to confine a mentally ill person who presents a danger to self or others. If a patient refuses medication and cannot be confined without endangering other



patients and staff, the court concluded that this would be one factor to weigh in overriding his or her decision to refuse medication. Secondly, although the doctrine of parens patriae permits the state to care for those unable to care for themselves, the court concluded that mental illness is not the equivalent of incompetency. Therefore, a state may use this doctrine as a basis for medication only if some type of hearing on the issue of incompetency has been held. Thirdly, a patient "may challenge the forced administration of drugs on the basis that alternative treatment methods should be tried before a more intrusive technique like psychotropic medication is used" (Dix, 1981).

Similarly, the compulsory administration of psychotropic medication was at ssue in Rogers v. Okin, a case now pending before the United States Supreme Court. In Rogers, the court held that patients have a constitutional right based on the due process penumbral right to privacy, bodily integrity or personal security to decide whether to submit to potentially harmful antipsychotic medication treatment in nonemergency situations.

In regard to emergency situations, the court held that where the situation involved a sufficient danger of physical harm to the patient or others, forcible medication is justifiable on the basis of the state's police power and no adjudication of the patient's competence is necessary. The First Circuit rejected the lower court's finding that only a danger of violence could justify emergency medication, holding that emergencies can constitutionally include some situations in which immediate administration of drugs is reasonably necessary to prevent deterioration of the patient's mental health. In such situations, the court found that emergency treatment is supportable on a parens patriae rationale.



Implementation of the Right to Refuse Treatment

Although both the Rennie and Rogers courts held that a patient has a qualified constitutional right to refuse treatment, each court suggested a different procedure for implementing this In Rennie, the court held that confinement and forced medication constitutes a sufficient liberty interest so that due Thus, in the absence of an emergency, a procèss attaches. hearing is required to insure that the use of medication in a particular case does not violate a patient's constitutional The court concluded that, in non-emergency situations, institutions which do not establish some type of independent administrative board to review treatment decisions must: 1) provide a system of patient advocates to be responsible for both analyzing cases where the treating physician certifies that a patient is incapable of providing informed consent and acting for the patient in obtaining independent review; and 2) provide informal review by an independent psychiatrist before forcibly medicating an involuntary patient.

In contrast, the First Circuit in Rogers held that where nonemergency treatment is at issue, the parens patriae power justifies compulsory treatment only following some type of determination that the patient lacks capacity to decide whether to submit to such treatment. The court indicated that if a guardian is appointed, she or he must make all treatment decisions involving antipsychotic medication. However, such decisions constitutionally must be made "with the aim of making treatment decisions as the individual himself would were he competent to do so" (634 F. 2d at 661). At this time, neither of the above-cited cases are directly binding on Texas state hospitals, although such hospitals will, of course, be required to comply with the substantive and procedural rulings of the Supreme Court when it renders its decision in Rogers.

4. PATIENTS' RIGHTS AND ADVOCACY FROM A LEGAL PERSPECTIVE

Karl Menninger II, J.D.*

During the last decade, the litigation on behalf of mentally ill and mentally retarded people in state institutions resulted in several court victories. In Wyatt v. Stickney, a federal judge declared that patients of Alabama's mental health-mental retardation system had, a right to treatment under the U.S. He ordered reforms affecting virtually every aspect of the hospitals' operations, from the patient-staff ratio to the censorship of patients' mail. Other lawsuits followed, based on the right-to-treatment theory, and many resulted in court orders for major improvements at state hospitals. In 1975, the U.S. Supreme Court, in the case of O'C. ..or v. Donaldson, declared that a state could not confine a non-dangerous mental patient without treatment. As the result of that decision and other lawsuits, a number of state commitment laws were held to be unconstitutional, because they did not provide enough safeguards to avoid unnecessary commitment.

Although many lawsuits attempted to improve all or most conditions at institutions, the issue in some was a single one; right of patients to be paid for suits established a institutional labor (Soulder v. Brennan) and a right to refuse psychotropic medication in non-emergency situations (Rennie v. Klein, Rogers v. Okin). The next stage in litigation attempted to move people out of the institutions. In Halderman v. Pennhurst State School and Hospital, a federal judge decided in 1978 that conditions in Pennhurst, a state institution for mentally retarded people, could never be improved enough to provide the residents adequate treatment. He found violations of the U.S. Constitution, federal and state law, and ordered Pennhurst closed. That decision appeared to open the way for a right to treatment in the community which would force the states to establish adequate community programs and placements.

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Such a right has not come about, however, and there are indications that it is unlikely to come about as the result of lawsuits. The major indication is the U.S. Supreme Court's recent decision in <u>Halderman v. Pennhurst</u> that there is not a right to treatment in the least restrictive alternative for mentally retarded people under federal law. That decision will have a major impact on litigation on behalf of the mentally ill, as well as mentally retarded poople, and it provides an opportunity to reflect on the use of the legal system to enforce patients' rights.

Pennhurst is the latest in a series of Supreme Court decisions that show a changing attitude toward patients' rights. In 1979, the Court issued two decisions that were considered by many advocates to be partial or major defeats. In Addington v. Texas, the issue was the standard of proof required for civil commitment. Although advocates for mentally ill persons argued that the standard should be the highest one, the Court decided that a lower standard was all that was required. That same year, in J.L. and J.R. v. Parham, the Court was asked to decide whether a trial-type hearing was required when parents want to commit their children. The Court held that a full-scale hearing was unnecessary; however, a psychiatrist should make sure that commitment is in the best interests of the child, and that the parents are not committing the child for their convenience.

On April 20, 1981, the Court issued its decision in Pennhurst. The Court of Appeals found a right to treatment in the Developmentally Disabled Assistance and Bill of Rights Act, a federal law which provides funding to the states. The Supreme Court reversed the Court of Appeals and decided that the federal law does not require states to provide treatment in the least restrictive alternative. The Court sent the case back to the Court of Appeals for a determination of whether or not there is a constitutional right to treatment.



In all these cases, there is a good deal of deference to state officials and psychiatrists and a reluctance to intrude in the operations of state institutions. The Court appears to be unwilling to endorse new patients' rights, such as the right to treatment, which are not mentioned in the Constitution. Its decision on the <u>Pennhurst</u> case shows an unwillingness even to enforce new statutory rights unless they are unequivocal.

In part, that attitude results from the conviction of some of the Court that there are some areas in which the law has only limited applicability, and one of those areas is in the public provision of treatment to mentally ill and mentally retarded people. In many of the suits, a non-legal problem (for example, lack of community placement programs) was framed in terms of legal rights (Does the lack of community placement violate the restrictive the least treatment in residents' right to alternative?). To some Justices, a lawsuit is not the best way, or even the proper way, to solve such problems as inadequate funding of services or lack of treatment programs.

Ironically, the "successful" lawsuits provide good evidence to support the belief. Virtually none of the major institutional lawsuits have ended. Ten years after the trial in Wyatt v. Stickney, much of the judge's order has yet to be implemented. In judge placed the entire mental health-mental the in receivership, an arrangement retardation system administration of the system is taken-away from the state and given to a court-appointed person. The judge cited "substantial and serious noncompliance" with the standards as his reason for the action. Another major suit was NYSARC v. Rockefeller, which was about conditions at Willowbrook, a New York institution for mentally retarded people. The judge appointed a special master to implement the standards. Recently, the legislature refused to fund the office of the special master, and the federal Court of Appeals uphold the action, thus effectively eliminating the There have been some master and the enforcement mechanism.



improvements, but most of the lawsuits have failed to induce the state to improve institutional conditions and treatment programs to the level required by the courts.

Until recently, the federal government took an active role in advocating for patients' rights. It was a party in many of the cases and provided funds for states to establish community The Mental "ealth Systems Act, passed in 1980, sets out a model bill of rights for patients and establishes a protection and advocacy program for mentally ill Reagan Administration's plans call for elimination or greatly reduced funding of those programs. federal government is apparently abandoning its advocacy efforts and leaving the matter up to the states. The states, in turn, have generally put a low priority on mental health-mental retardation services in the past. Given reduced funding and less incentive from the federal government, they will probably continue to do so.

The implications of the government's low priority on such services are obviously disturbing to contemplate in terms of how it will affect the mentally ill and mentally retarded people who need treatment but cannot afford private hospitals or doctors. Just as disturbing, however, is the philosophy of government that this represents. Should not our government help those who cannot help themselves above all others?

The changing political and judicial attitude toward patients' rights and public mental health-mental retardation services may necessitate changes in the use of courts. If more judges adopt the Supreme Court's view, the lawsuit will become an ineffective method of social reform. Instead, it may be used primarily as a way to enforce established rights rather than to create new ones. Courts may then avoid deciding questions that involve allocation of state resources, operation of state agencies or other complex matters which may be more than simply violation of rights.



There may also be a change as to what the lawsuits are attempting to achieve. The ultimate goal of most of the major suits was to get as many people as possible out of state The suits involving civil commitment procedures institutions. prevent unnecessary commitment designed to The right-to-treatment cases were primarily institutions. brought to improve institutional conditions, but they also proposed the theory that if the state was not going to give someone treatment, that person should not be in the institution. Finally, in Pennhurst the institution itself was on trial. Although the Supreme Court's decision does not eliminate all legal theories of deinstitutionalization, it makes it very difficult, since the Court's lack of sympathy for such efforts was clear. In the future, the successful lawsuits may address much narrower issues than the liberation of all patients.

These factors should lead advocates of patients' rights to have lower expectations of the movement throughout the next decade. It is apparent that the initial round of court victories is not the fast and easy solution for which many hoped. The state legislatures_spend the money, and it is in the legislatures that advocates should work to bring about increased funding for mental health-mental retardation programs and laws setting patients' bill of rights, grievance procedures, and other standards that ensure adequate care and treatment. Lawyers can then use the courts to enforce those rights, and the courts should be amenable to such suits. In that limited role, rather than the "cutting edge" role it played in the 1970s, the legal system can be a forum to ensure at least minimal standards of treatment for mentally ill and mentally retarded people.



SECTION II =

Texas as a Case Study.

5. CLIENTS' RIGHTS

John J. Kavanagh, M.D.*

The Texas Department of Mental Health and Mental Retardation (TDMHMR) has a moral and legal obligation to make certain that the rights of clients served by our facilities are protected consistently. This obligation extends to all clients. It is their assurance that they will receive humane and decent treatment and that their legal rights as citizens are protected adequately.

For many years the role of guarding clients' rights was determined largely by the superintendent or director at the state mental hospital or state school for the mentally retarded. Early in the 1970s, however, the Joint Commission on Accreditation of Hospitals (JCAH) began emphasizing the necessity of a humane, pleasant and comfortable environment in treatment areas.

JCAH standards also stress that public facilities for the mentally ill must dedicate and use the maximum resources possible to enhance and improve clients' care and treatment. In Texas, these JCAH standards contributed greatly to the many treatment program advances, but it was not until the Wyatt vs. Stickney court judgment in Alabama that certain rights legally were required and could be expected by clients of all state mental hospitals. Other court decisions helped establish laws that entitle mental hospital clients throughout the nation to certain rights and protection.

In 1974, Kenneth D. Gaver, M.D., the TDMHMR Commissioner, appointed several task forces, composed of Department mental health professionals, to begin a study that would result in policy to govern the protection of the clients' rights. In his charge to the task forces, Dr. Gaver called for the provision of

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standards to ensure adequate and humane treatment, to avoid undue or intrusive treatment, to protect the rights of clients who are research subjects, and to eliminate undue activity restriction or restraint. This action did not imply that the facility administrators had not pursuaded fervently the implementation of professional treatment standards for hospitals and those recommended by the JCAH.

The task forces met periodically in 1974 and 1975 to prepare and exchange drafts of their proposals. These were distributed to mental hospital personnel, advocacy group representatives and private citizens for their review, comments and criticism. Dr. Gaver's order accomplished the production of written documents and rules that now apply to the entire mental hospital population of the Department.

When the Texas Register Act became effective in January 1976, the completed rules were adopted and became the Rules of the Commissioner. Since that time, the rules have been improved and amended, as a result of suggestions made by those actively engaged in client treatment and by advocacy group representatives who monitor programs for the mentally ill offered by the Department.

As the Rules were developing, it was decided that the legal language used by attorneys in interpreting the law and court decisions would be inappropriate in the planned publication for distribution to each client and for posting in the treatment areas. It was agreed the Rules should be in lay language that would be understood readily by clients, their families and employees. During this process of simplification, there were many interpretations to avoid jargon and limit technicalities that might make a rule confusing or difficult to comprehend.



The result of this effort is a small, pocket-size publication, "Your Rights and Privileges in Facilities of the Texas Department of Mental Health and Mental Retardation." Printed in English and Spanish, the book is highlighted with drawings to emphasize some major points. A copy is presented to each client at the time of admission, or as soon after as is practical.

The Department's Standards Compliance and Quality Assurance staff members monitor the adherence of facility personnel to the Rules when they make routine inspections. Thus, the protection of the rights of the mentally ill in Texas is continuing to be guarded in the Department's treatment facilities.

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6. PATIENTS' RIGHTS: THE PERSPECTIVE OF THE MENTAL HEALTH ASSOCIATION IN TEXAS

Al St. Peter, J.D., and Shirley K. Camfield, R.N.*

He was a salesman on an ordinary flight trying to make ordinary conversation.

"What do you do?"

"I'm an attorney; working in mental health law.".

"I didn't know there was such a thing. What do you actually do?"

"Oh, I've done some work in patients' rights."

"Patients' rights? I didn't think patients had any rights."

The conversation occurred somewhere over Temple, during May, Mental Health Month, 1981. The attorney was a board member of the Mental Health Association in Texas, and the salesman learned that mental health patients did, indeed, have some rights.

Ordinary citizens banded together in 1934 as the Texas Society for Mental Hygiene to advocate for patients rights. In those days "patients' rights" meant getting decent care in a decent environment. Forty-seven years later, the Texas Society operates as the Mental Health Association in Texas, part of a nationwide volunteer movement to promote mental health. Our nation's ideas about what constitutes decent care in a decent environment have evolved, but the concept is still a primary thrust of the organization. Today we know that hospitalization is not the answer for everyone's mental health needs. For many people there are better alternatives, and care in the least restrictive setting is preferred.

^{*}St. Peter is the President and Camfield a past president of the Mental Health Association in Texas, headquartered in Austin.

The Mental Health Association believes that it is the duty of the State Government to afford each person in need of mental health care such services as are adequate, appropriate, and consistent with concepts of human dignity and personal autonomy. From this philosophical viewpoint grew our 1981 State Legislative platform. It is basically what the Association advocates for at the local, state and national levels.

Texas' 17 local affiliates work at the community level -providing seminars and information about mental health topics and
issues, influencing the local government to fund community mental
health services, appearing on talk shows to help eliminate the
stigma attached to having mental health problems, and other
similar strategies.

The state and national levels of the organization each pursue patients' rights and advocacy in accordance with their roles -- through litigation, legislation, education, or other means. The National Mental Health Association has been involved in nineteen court cases since 1972, five of which were argued before the United States Supreme Court. One of the Supreme Court cases was in our own state, Addington v. Texas, which concerned the amount of proof required to commit an allegedly dangerous person to a mental institution. Of significant impact to the Texas mental health delivery system is the recently settled suit, R.A.J. v. Kavanagh. Amicus in this seven-year case was the Mental Health Association of Dallas County.

Our National Association's involvement in litigation goes to the heart of patients' rights issues, including the right to treatment, rights of patients in mental institutions to be compensated for their work on behalf of the institution, opposition to the impoundment of mental health funds, protection of the confidentiality of patients' records, safeguarding patients' rights regarding commitment, the right of discharged patients to live in a particular community, and a number of other.



issues of fundamental importance to persons who are, or have been, mentally ill. Currently, the National Association is amicus in Rogers v. Okin, which concerns the rights of involuntarily committed patients to refuse medications. In the same vein, the Texas Association, during the last State Legislative session, supported a bill which would give mental patients the right to refuse therapies which cause convulsions:

There is an impressive body of case law and legislation (such as the Civil Rights of Institutionalized Persons Act, which allows the Justice Department to intervene where a patient's civil rights may have been violated). An important role of citizens' advocacy groups is to see that these laws are implemented. For example, in R.A.J. v. Kavanagh, the judge did not just say "obey these laws." The judge called for a three-person panel to work for three years to see that the Texas mental health system is modified and that patients receive their rights as stipulated in the settlement.

The role of citizens in monitoring services is important. Projects such as the evaluation of the local community MHMR center by the Mental Health Associaton of Tyler brought about some needed changes, such as night hours. Their evaluation process is continuous and has developed into cooperative efforts The strength such as seminars. other programs organizations such as the Mental Health Association is that they are composed of citizens -- people from all walks of life who have an interest in a particular cause. Many of our members have had a family member with a mental health problem, or they have experienced it themselves. We speak from a consumer point of view, which is especially important when we are advocating for change.

In addition to working on behalf of persons who are mentally ill, the Mental Health Association is currently initiating an exciting self-advocacy project statewide, Family and Individual Reliance (F.A.I.R.). We are establishing mutual support groups for families of mentally or emotionally disturbed persons, and



also separate groups for individuals who have experienced mental problems. The response to the concept and the project has been wonderful. There are support groups (under various names) in Austin, San Antonio, Dallas, Beaumont, Fort Worth, Longview, Galveston, Abilene, Freeport-Lake Jackson and Houston. Several other areas are about to initiate self-help groups. These local efforts are just one part of our total mission to advocate for needed changes at all levels - nationally, locally and statewide.

Looking towards the future of patients' rights in Texas, the Mental Health Association is calling for a revision of the Texas Mental Health Code. A new Code is needed because the rights of patients are not listed in one place. Some rights are outlined in the Code, some in statutes, many in the Commissioner's Rules and in the Joint Commission on Accreditation of Hospitals' standards. In the judge's decision on R.A.J. v. Kavanagh alone, twenty different patients' rights are specifically mandated. A new Texas Mental Health Code would bring these rights together.

During the 1981 State Legislative session, an impressive array of citizens joined forces to promote a bill which would have provided for a legislative committee to rewrite the Texas Mental Health Code over the next two years. The Mental Health Association allied with members of Citizens for Human Development, the Texas Society for Autistic Citizens, the Texas Council of Community Mental Health Mental Retardation Centers, Advocacy, Inc. and the Texas Association for Retarded Citizens to see that our outdated Code would be updated.

These organizations are inviting other's from the public sectors to continue in pursuit of a revision of the Code following the State Legislative session. One way or another, the Association will work for an updated Texas Mental Health Code to be presented for legislative approval in 1983. The Mental Health Association in Texas considers a revision of the Texas Mental Health Code as the most important step in Texas to safeguard patients' rights in the future.



7. "MEXICAN AMERICAN MENTAL HEALTH: ISSUES TO ACTION" CONFERENCE THE PATIENTS' RIGHTS AND ADVOCACY WORKSHOP

The IDRA's Mental Health Research Project Conference, "Mexican Americans and Mental Health: Issues to Action," held May 1-2, 1981, in Austin, included a workshop on Hispanic Patients' Rights and Advocacy.* The contributors to the workshop, Louis Kopolow, M.D., Chief of the Patients' Rights and Advocacy Section at the National Institute of Mental Health; Karl Menninger II, J.D., an attorney at the Center on Developmental Disability Law, Kansas City, Missouri; Shirley K. Camfield, R.N., Presicant of Citizens for Human Development, Austin, Texas; and Alfonso Lopez-Vasquez, M.Ed., of the Mental Health Research Project, presented background information on patients' rights and diverse perspectives on advocacy.

Dr. Louis Kopolow spoke primarily about advocacy: the need for it, the forms that it can take, and how it can function. pointed out that the Report of the President's Commission on Mental Health in 1978 acknowledged that even the best efforts at deinstitutionalization had resulted in abuses and exploitations not unlike those that deinstitutionalization had been intended to .. circumvent. The difference was that the abuses and exploitations began to take place outside of the hospital; the abuses had been deinstitutionalized with the patients. The Report called for The need for advocates is advocacy on behalf of patients. particularly strong since the mentally ill have historically been the lowest priority of our society. Advocacy is a service that must be provided for the mentally ill, as they are typically incapable of demanding the service and do not have a powerful lobby to demand it for them.

^{*}This is perhaps the first time the topic has been highlighted at a professional meeting. The MHRP thanks the panelists for their contributions and the workshop facilitators, Alfonso Lopez-Vasquez, M.Ed., and Mary B. Bowman, Ph.D., who recorded the session.

Advocacy, Kopolow stressed, is not necessarily adversarial in character, although it often must become adversarial in practice. Rather, advocacy is literally "speaking on behalf of someone" and representing the interests of someone. This presents the lifficulty of whether the advocate's job is to represent the patients' wants or needs. Does the spokesperson advocate what he or she believes the patient needs, or what the patient wants? There is, of course, no easy answer to this problem, but any advocate should be aware that he or she will eventually face this conflict.

Kopolow advanced the idea that the purpose of the advocate is to empower the patient so that the individual can take control of his or her own life. It is thus important that the patient be an active participant in the efforts of the advocate and not, simply a passive recipient of the advocate's services.

In addressing the need for advocacy, Kopolow discussed not only the failure of the deinstitutionalization efforts, mentioned earlier, but also the extreme vulnerability of the mentally ill. They are the most underrepresented group, as well as the group most in need of representation. The nature of their situation accentuates their vulnirability in that they are dealing with authoritative experts (physicians and psychiatrists), around whom most people feel easily intimidated. But if one is also uniquely incapable of expressing oneself and is not taken very seriously anyway -- both typical conditions of mental illness -- one's submission is amplified. Mentally ill patients are also assumed to be ither incapable of or without the right to make decisions about their lives, and the things that they do or say are very often distorted through "interpretation." This makes it clear that the mentally ill person is not in a very good position to take power over his or her life. Furthermore, the arena in which he or she would be attempting to exercise this power is the mental health system, which is complex and difficult to negotiate regardless of one's mental or emotional state.



Kopolow outlined the most important characteristics of an effective advocate as having a willingness to help another human being, a willingness to take risks, to fight, and to "rock the boat." He characterized good advocates as "feisty". They do not accept defeat, and they are creative, imaginative, forceful and diplomatic when seeking their goals. An example of the styles that advocacy may take is the lawyer-advocate who finds that he or she often does not have to fight the patient's battles in court; often the mere threat of litigation can be a powerful persuader.

Advocates can either be external to the system, as the legal advocate usually is, or they may work within the system. Many hospitals provide patient-advocates. The internal advocate, however, must be granted certain powers if he or she is to he successful. He or the must be able both to refer problems upward in the hierarchy of the hospital, and to refer problems out of the system (to the courts, for example). Kopolow stressed that the two most important roles for the patient-advocate currently are promoting public education and legislation protecting the rights of patients.

Karl Menninger II spoke about a specific sort of advocacy -legal advocacy. Menninger pointed out that the courts'
acceptance of advocacy has been recent. It was only 27 years ago
that Brown v. Board of Education was decided, and only ten years
ago that Wyatt v. Stickney was decided. Before these cases, law
had the rather singular purpose of preserving existing social
order; reform was not a widely recognized purpose of the law.

Because the issue of patients' rights is such a relatively new one, courts have not yet addressed the special problems of racial minorities who are mental patients. Nonetheless, broader advances have been made in patients' rights. The most obvious of these has been in the narrowing of civil commitment procedures and rules. Twenty years ago, all that was needed for civil



commitment in most states was an opinion by virtually anyone, a relative or neighbor, for example, that someone was acting oddly. Due process has now been called strictly into play to regulate what is recognized as a serious breach of someone's liberty. Civil commitment proceedings are still being modified and usually narrowed.

Menninger pointed out that regardless of what rights are legislated for the mentally ill, these rights are meaningless if the patient cannot understand them. This is especially problematic in the case of the non-English speaking patient, but is to some extent a difficulty of all patients. In the case of the non-English speaker, the problem can be at least attenuated by the required presence of an interpreter, but to his knowledge only Kansas has asserted due process ground for an interpreter to aid in explaining patients' rights to them.

Beyond the indirect discrimination which the minority patient may be subjected to, there is also outright discrimination. The forms that this takes are often subtle and include such things as the type of treatment provided for different patients. Menninger stressed that litigation which prohibits direct discrimination is vitally necessary, but that it will not solve the problem of indirect or subtle discrimination.

Shirley K. Camfield presented an account of what it means -and does not mean -- to be an advocate. Camfield has had a great
deal of experience in the field, and she instructed the group on
methods, strategies, and even some ploys for advocacy.
Camfield's strongest message was that the advocate must work
within the system, and that he or she must be a credible and
informed authority on diverse aspects of the system. Maintaining
credibility is a major rule of advocacy, and she stressed the
need to deal with people honestly and directly and to achieve
one's ends in ways that do not abuse the people with whom the
advocate interacts. Camfield said that the advocate must realize



that compromise is necessary in advocacy. One should be assertive rather than aggressive and pliantly firm rather than rigid.

The advocate must have a constituency; that is the source of their power. The constituency must be built slowly, over time. It demands establishing one's credibility with the constituency and maintaining contact. Similarly, working relationships within the system must be built slowly, with an emphasis on establishing and maintaining credibility. Camfield noted that one of the reasons that skills in building a constituency are so important is that it costs money to organize and carry out advocacy, and an advocate's main source of financial support is his or her constituency. Thus, the constituency must be made a part of the advocacy process.

Camfield emphasized that it is important to set goals that are achievable. Nothing is gained, and much is lost, in absurd This is not to say that one should never ask for more than one is likely to get. Negotiating often involves a cushion of expendable goals, but the goals themselves must never be pointlessly gradiose. Advocates deal with people with vested interests (other advocates, lobbyists, and legislators) and all will have their own "pet" projects. The skilled advocate learns how to help these people achieve their goals and finds that, in so doing, he or she gains powerful allies. Nonetheless, outright conflicts are unavoidable. Diplomacy is important here. Often it is valuable not to foster opposition to one's goals. As Camfield said, "You don't go out and pick fights; that is, you don't create conflict where you don't need to, but you don't run from conflict either". One must learn to negotiate conflict.

Conflicts also occur within the advocacy group. Camfield stressed the importance of completing the infighting before the group presents its goals to the public. It is vital that the advocacy group appear as a united body. Conflicts are resolved



internally and privately. This demands that the members have mutual respect for one another's interests and that they support one another.

The most effective lobbyist, Camfield said, is the articulate ex-patient, and recruiting ex-patients as advocates is a good strategy. It is important to develop local leadership and community strength. However, Camfield warned against excluding the service provider, whose cooperation and support can be vital. The key to a powerful lobby is a contituency that can be mobilized. Unity, she stressed, is the most important goal.

camfield stated that there is hope for the advocacy movement even in this time of limited financial resources. A great reservoir of untapped resources exists in the corporate world. Issues of mental health are of legitimate interest to the corporate world, which is beginning to understand the impact that alcoholism, substance abuse, and other forms of mental illness can have on productivity and efficiency. They are often willing, therefore, to support advocates in promoting mental health and ought to be seen as valuable sources of support.

Alfonso Lopez-Vasquez presented an analysis of the generalizability of Title VI of the Civil Rights Act of 1964 from education to mental health. Basing his analysis primarily on interpretations of the Civil Rights Act as it relates to national origin minorities, and especially on Lau v. Nichols, which mandated equal educational opportunity for non-English speaking students, Lopez-Vasquez explained that if the decision and related cases can be validly generalized from education to mental health, it is clear that the mental health systems in most states would be in violation of their requirements.

Specifically, Lopez-Vasquez pointed out that there are at (least three linguistic categories of Hispanics: Spanish speakers, bilinguals, and English speakers. Lopez-Vasquez noted



that many cultural aspects are correlated closely with these linguistic categories, and that these linguistic categories and their attendant cultural aspects have a profound effect on the treatment of Hispanics in mental hospitals and other institutions. Since the mental health system does not recognize and provide for these groups, they are not meeting the guidelines set forth for education in Title VI. Lopez-Vasquez suggested that patient advocates can thus begin to draw from the precedents of educational law.



8. MEXICAN AMERICAN THERAPISTS SPEAK OUT ON PATIENTS' RIGHTS

by Rosa Maria Moreno, M.Ed.*

Author's note: The following material is based on interviews with fifteen Hispanic mental health service providers in Texas who are involved in direct services to Mexican American clients. All but one were Mexican American. Among those interviewed were psychiatrists, social workers, psychologists, master's and bachelor's-level mental health workers, and several non-degreed service providers. The respondents were employed in a range of settings, from community mental health centers and state mental hospitals to non-profit multi-service community centers, in locations across the state which included San Antonio, Dallas, Houston, El Paso, Corpus Christi, and the Lower Rio Grande Valley.

The focus of the interviews was to gain the perspective of the Mexican American service provider regarding the impact of the patients' rights movement on the Mexican American client and to identify issues which arise from the uniqueness of the Mexican American experience in treatment. This was not intended to be a systematic, empirical sample or survey, but rather a preliminary delineation of some of the views held by several widely respected Mexican American therapists in Texas on the topic of patients' rights. The author has attempted to point out both similar and constructing views among those interviewed. It should be noted, however, that the views presented in this article do not necessarily represent the views of the author nor of IDRA.



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El gobierno tiene mucho poder. Although it would be overgeneralization to say that Mexican American mental health clients subscribe to this old adage, it is a thread that runs throughout the various conversations that the author had with Mexican American service providers in Texas. worker, in particular, believes that this phrase reflects the Chicano client's view of the mental health system. colleagues throughout the state also allude to the fact that Mexican American clients tend to be less assertive and even fearful in exercising their rights as patients because they are skeptical that they really possess such rights. Even when explained to them sufficiently so that they understand their rights, many clients still question whether or not this is just another bureaucratic "Catch 22." The more traditional, older Mexican American clients especially remain somewhat dubious that they will get the type of service they need. As one Mexican American therapist suggests, "They feel that what there is, is Many clients share a basic distrust and what they get." suspicion of the institutions, whether they be governmental or community-based centers, based on years, and in some cases, injustice, and, neglect. discrimination, of Skepticism may be based on a sincere belief that they will not actually receive any help or that they will not be understood; whereas fear surfaces in a feeling of helplessness, as reflected in the question, "Will I be sent away (put away in a hospital)?" In essence, the provider -- el gobierno -- is perceived as having the power to dictate their fate in the receipt of care by a system that allows entry only on its own terms.

A comewhat contrasting outlook is presented y a mental health worker who suggests a more positive, forward-looking view. Gomez says of the Mexican American that, "We as a population are finally getting the feeling that it is okay for us to demand from our government to do what we want...," in essence, to listen and to provide the services needed. Perhaps this is the primary message that the patients' rights movement can transmit to the Mexican American client.



Is this message being perceived, however, by the Mexican American that comes into contact with the treatment process? Twelve of the fifteen Mexican American professionals interviewed indicate that most of their clients are not aware of their rights as patients, and all allude to the need for having patients' rights explained in the dominant language of the client. But as a reports, "Explaining does guarantee It is the staff person's responsibility to see understanding." that the client actually understands what those rights are and for the client. Ιt means cutting across they mean socioeconomic, educational, language, and cultural barriers to assure that clients comprehend their rights. When a client is informed by being handed a piece of paper to read, whether in English or Spanish, as is often done, this is not enough. clients are illiterate or not sufficiently literate, in either Spanish or English, to comprehend such materials. Those that are literate may not understand the particular terms used or the implications of the statements. Such a lack of comprehension is compounded by the problem common to some mental health clients, i.e., their condition or mental disturbance is so severe as to impair any reasonable expectation of understanding. The 1980 Mental Health Systems Act presents a model patients' rights statement, however, which emphasizes the right of clients to be informed of their rights not only initially but also periodically throughout the treatment process.

Assuming that the client is fully cognizant of the rights he or she possesses, in the case of the Mexican American client, several of the professionals interviewed reiterate that the staff must go further to break down the generations of prejudice and discrimination experienced by Mexican Americans and to dispel the general mistrust held by them of Anglo institutions. The reluctance shown by many Mexican American clients in asserting their rights, Estrada says, is because, "Mexican Americans need to believe in their rights, that they have rights before they can actually exercise those rights." Especially in areas such as the



Rio Grande Valley of South Texas, it takes a special effort on the part of mental health workers to make clients realize that they do have the right to participate in their own treatment planning, in asserting grievances, in maintaining confidentiality, etc. It is not until clients actually "test the system" or the sincerity of the staff -- "Let me see my record" or "Let me see what you're writing" -- that a Chicano client might begin to understand his or her role as citizen/consumer/patient who possesses civil, human, and legal rights within the mental health treatment process, rather than just being a participant in that mysterious and usually novel experience known as therapy.

Clients cannot be expected to be aware of their rights as patients, however, if staff are not fully cognizant of those rights themselves. As is reflected in various comments made to this author, staff members of mental health programs do not receive adequate training concerning patients' rights, yet they are expected to adhere to those rights and to transmit them to their clients.

One Chicano counselor claims that a client's desire to rights is sometimes obstructed assert his or her defensiveness of clinicians, who although they recognize and acknowledge the rights of the patient, feel threatened when the client may request to see his or her record or to review a treatment plan. Clinicians sometimes assert the right to deny these entitlements to a client on the grounds that, "It might be psychologically detrimental, although he (the clinician) may really be protecting his clinical judgment, protecting what he has saida" As Martinez, a San Antonio psychiatrist, explains, the patient can exercise the right to participate in treatment planning by simply asking questions, but, "The average patient is fairly passive; he is in the 'patient' role, ... and most patients are treated authoritatively by caretakers." In addition, it is very difficult to participate in the planning of treatment when one does not understand the language being used in therapy or the



context and process of therapy itself. He goes on to say that within the patient group, Blacks and Mexican Americans are treated with even more authority and domination: "They are an oppressed minority within a repressed group."

Perhaps the most controversial and yet most central issue for Mexican American patients! rights is the right to treatment, which is interrelated .with the provision of appropriate and effective care. Right to treatment is discussed by some of the providers in terms of several factors: 1) the right to know that treatment is available, i.e., that the Mexican American community needs to be informed about what services are available to them; 2) the right to treatment in an appropriate, non-threatening setting, one in which the client feels comfortable, hence the need for more outreach efforts and therapy conducted in the home and neighborhood centers; and 3) the right to effective, quality qualified many cases which ' treatment, in bilingual/bicultural therapist.

Several of the therapists interviewed indicated that clients should be given a choice in selecting the setting or environment Therapists should be amenable to providing for treatment. services to the Mexican American client in a non-threatening environment, one in which he or she may feel comfortable, even if this means conducting therapy away from the clinical setting, such as in a neighborhood center or in the client's home. Because many Mexican American clients do not currently know what services are available to them or are uncomfortable in coming to the services, some Mexican American 3 health center for therapists assert that the right of the client to treatment can be interpreted to mean that clients are entitled to outreach services in order to obtain the therapeutic help they need.

The right to treatment, according to several providers, implies that treatment should be conducted in a language which the client comprehends and, according to one bilingual/bicultural



counselor, "Treatment should be culturally relevant, with programs geared to take into account the many elements that relate to the specific needs of the Mexican American."

The provision of services in a language the client understands may appear to have a simple solution at first glance. Bilingual therapists that can provide services in English and Spanish to clients seems to be the obvious answer and one which has been proposed by Mexican American advocates for many years. However, there are still mental health centers that available few, if any, bilingual therapists. Many of the individuals interviewed state that their own organization does not have this problem, but they report that other agencies in Lingering attitudes of prejudice do. discrimination partially contribute to this, and feelings among Anglo administrators and the general public that the Mexican American should adapt to the system as it is, are still In addition, few alternate solutions to the hiring and training of bilingual therapists have been proposed or proven effective.

A family therapist acknowledges hearing time and time again, that, "Treatment is treatment, and if it's effective, it is effective for everybody, whether they be Black, Mexican American or Anglo." In his experience and from his knowledge of the mental health field, this has not proven true. The Anglo professional who cannot bridge the language and cultural gaps between himself or herself and the client, according to this counselor, may actually be doing more damage to the client than if the client receives no therapy whatsoever. At times it becomes, "...a matter of whether our concern is more with meeting the counselor's needs rather than the client's needs."

Serving the Mexican American client also means addressing the heterogeneity of this ethnic group. Not only must the monolingual Spanish-speaking client and the bilingual Mexican American be adequately served by the mental health system, but



the needs of the monolingual English-speaking Mexican American client must also be acknowledged. Several of the Mexican American professionals interviewed point out the importance of the therapist's not making assumptions about the client, not bringing preconceived notions to therapy, or inculcating his or her value system into the treatment process. This is an area where both Anglo and Mexican American therapists alike must recognize that although "culture cannot be separated from the person," each client must be seen as an individual.

In addition, subcultures within the Mexican American population must also be recognized and a therapist must be familiar with their existence and their implications for therapy. One example discussed by a Valley social worker is the "low-rider" phenomenon. Mental health workers need to keep abreast of the evolvement of culture, lifestyles, and attitudes in their communities. Another counselor adds, "It is not just enough to be Mexican American. If you are going to serve your people, you need to be extra culturally aware, extra sensitive; you need to be aware of where you are in the bilingual/bicultural continuum, and be aware of where your client falls on the continuum."

The experts consulted through our interview process agree that Mexican American clients have a right not only to treatment, but also to offective and appropriate treatment. Most of the Mexican American therapists surveyed concur that this usually means culturally and linguistically appropriate services provided by a bilingual/bicultural therapist. The issue of quality care means that, "Treatment should be in Spanish for those who are only Spanish-speaking, and only with a therapist they feel comfortable with. If a client uses Tex-Mex lingo, then someone who understands this, speaks it, and understands its cultural context should be available to provide therapy."



Problems occur when language and culture are not taken into One provider interviewed account in the treatment process. related the following example: "A therapist may want to provide treatment that goes against the culture of the individual," such when "...an individual has been seeing a curandero (folk healer) and the treatment plan prepared by the therapist includes no longer going to a curandero." Although the therapist may not see that this creates an internal conflict for the client, it may be something quite serious for the individual. Another therapist concurs, "Quality of care means that we include in treatment modalities which people are comfortable with, knowledge of and have faith in, such as curanderos and yerbitas (medicinal herbs and plants). Centers do not always validate, sanction this, make it an okay kind of thing." The result is that some clients may be discouraged from returning to treatment and may be reluctant to open up with the caseworker or to follow through with portions of recommended treatment plans.

Of the providers interviewed, several assert that the right to appropriate treatment for the Mexican American includes the right to be consulted in the assignment of a therapist. should be the right of the client to choose the counselor," says one family counselor. It is important that the clients be someone who speaks their language matched with understands their culture and value system. Oftentimes the sex of the therapist is also of concern to the client. Several social workers alluded that it is "very difficult for someone of another culture to work with the Mexican American." One therapist expresses that he "feels somewhat pessimistic about transmitting culturally relevant information to a person who is not involved in a very personal way" with the culture and the people. "I think the best way... is to hire Chicanos... and do case assignment that meets the cultural needs" of the client, because if caseworkers "...do not have the afeccion (affection or fondness) or respeto para la cultura (respect or esteem for the culture or way of life), 'if they don't feel it in a very personal way, you just can't transmit that feeling in treatment if it's not there."



An almost equal number of the providers interviewed remark that Anglo therapists could provide appropriate treatment services to the Mexican American population in they spoke Spanish, were attuned to the specific cultural characteristics of the client, and did not make assumptions based on stereotypic knowledge of the lifestyle or values of the Mexican American.

Other patients' rights issues were raised by the providers contacted through the interview process. As one counselor comments, "Medication is an issue; the poor and the Mexican American client are medicated more than other clients, but the risks are not explained nor are they oftentimes told what the medication is for, how it will help them. This is a disservice to the client, especially once they are at home."

other major issues discussed by the mental health Two the right interviewed were that professionals confidentiality and the role of family involvement in treatment. As Zapata and Gomez explain, confidentiality in therapy poses a conflict for many therapists and clients alike in that, "Many Mexican American clients have a difficult time understanding why they have to sign in order for <u>la abuelita</u> (grandmother) or <u>la tia</u> (aunt) to know what is going on with them in treatment." The two conflict between encountered counselors have abuse preserving the client's right to confidentiality and the extended family's concern for the client. In many cases, the family's involvement in therapy can be beneficial, but conflict arises if the client's confidentiality is to be protected. An additional example is given by another therapist of the conflict which arises between protecting the client's right and addressing what the family feels is its right to be involved. According to her,

Sometimes ...in protecting individual rights, in treating the individual as an isolated unit, you violate families' rights. One of the primary things about a family is that they function as a unit and they have certain assigned tasks.



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People have to know what is going on with one another in order for those functions to take place. As we regulate individual rights more and more, we take family rights away more and more. Take the case of children and teenagers, in particular, in trying to protect the rights of a sometimes you violate the teenager, rights of those parents, in that something may be going on that it may be useful or helpful for the whole family involved in, but because of the way that teen feels, you would be violating the client's confidentiality. Where do you Where do you The same thing happens draw the line? with husbands and wives...

How to involve family members appropriately in a therapeutic way withou violating patients' rights is an issue which has not adequately been addressed by advocates or providers.

The majority of the Chicano therapists interviewed, however, call for more family therapy to be conducted with the Mexican American client. Because of the importance of family to most Mexican American clients, family involvement in the treatment process is important to the provision of appropriate or culturally relevant care. The patient and family must be willing, of course, to participate in family therapy, but as Flores points out, "Too often the family gets left out because the therapist is not adept at it, doesn't want to bother, or is uncomfortable doing family therapy." He believes very strongly that it violates a patient's rights if the therapist cannot provide quality family therapy when it is requested or indicated.

Several therapists mention that Mexican American clients and families tend to wait to seek help until a client's condition became severe and that families tolerate a greater variety in behavior. This often leads to limited alternatives to treatment when the client finally does come in contact with the mental health service delivery system. It basically means that at the point of entry into the system, the right to the least

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restrictive setting is not really an option for the individual. The severity of the condition indicates hospitalization.

A psychologist interviewed by the author notes that the right to the least restrictive environment is an important one "People should be cared for in the for Mexican Americans. facility closest to their home. However, for many Mexican Americans, especially from areas like the Rio Grande Valley, they are not treated close to their home community. They often end up in the San Antonio State Hospital and, therefore, it raises the issues of the right to have visitors, especially family, or the right to communicate with others outside the facility," since the typical Mexican American in the Valley cannot afford the economic expense to be traveling or making long distance calls to maintain contact with the patient. The psychologist explains further that the right to the least restrictive setting issue is complicated by the fact that many Mexican American clients may not have needed to be admitted to a mental hospital in the first place. But because Mexican American patients are not aware of other. services available, do not have access to these services, are not appropriately treated because of language and cultural barriers, simply because resources are not available in the home community, these clients do not really have the option of the least restrictive care.

Summary

...normality and abnormality are not universal What is viewed as normal in one culture may be seen as quite aberrant in another. (Rosenhan, 1973)

The impact of language and culture on the therapeutic treatment process has been the subject of speculation and research for some time. With the expression of the rights of patients in mental health systems, however, only a few have raised questions on how language and cultural issues interface



with the advocacy issues of patients' rights. Based on her years of experience in the field, a social worker expresses her frustration in no uncertain terms, saying that she, for one, is "sick and tired of the rights and issues of Mexican Americans in mental health being addressed only by the Mexican American professional. It should be something of concern for everyone in treatment, and not just those providing treatment, but also for administrators, program directors, and others." Until the fact that Mexican Americans do experience situational, cultural, socioeconomic and language differences is acknowledged rather than ignored or dismissed by the majority of mental health professionals, the treatment process for the Mexican American client will not be an issue of the patient's rights, but rather of his or her denied rights.

As to the eventual impact of the patients' rights movement on Mexican American clients, Martinez anticipates that it will have more effect on the way therapists and lawyers view these issues. He hopes "that patients' rights will make providers reluctant to use diagnoses that may be false, especially since the Mexican American patient tends to be diagnosed incorrectly more often than others."

A San Antonio family therapist stresses the importance of more research, training, and evaluation of mental health services for the Mexican American. "Given all we know about psychology and psychiatry," he says, "we know very little about how these theories apply to the Mexican American."

Among the areas where patients' rights problems are likely to occur, providers interviewed mentioned as the most serious or recurring ones to be:

1) the right to be adequately advised of rights,



- 2) the right to access and availability of treatment,
- 3) the right to confidentiality,
- 4) the right to appropriate, effective care,
- 5) informed consent, as related to both research and treatment,
- 6) the right to participate in the development of treatment goals,
- 7) the right to the least restrictive environment, and
- 8) the right to a fair and just commitment hearing.

All of the above interrelate to a great degree with the unique language and cultural characteristics of the Mexican American population. For Chicano clients, the issue of linguistically and culturally appropriate services is intertwined with the attainment and full exercise of their rights as participants in the mental health treatment process.



FOOTNOTES

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Translated literally the phrase means "the government has much power"; however, as used here, it refers to the power or control of any social institution or agency, whether government-controlled or quasi-governmental in nature. Thus, a more appropriate translation is "the system is very powerful." Vallejo, based on her interviews with Mexican Americans in California, reports that, "gobierno is the term used to define institutions which are not part of the barrio but which definitely do infringe on the individual's life in the barrio," in particular the "bureaucracies and power-holding systems" (Vallejo, 1971).



SECTION III
Conclusion

9. THE VULNERABILITY OF HISPANIC MENTAL HEALTH CLIENTS: CAN "PATIENTS RIGHTS" EXPAND TO ADDRESS THEIR NEEDS?

Sally J. Andrade, Ph.D.*

It is difficult to summarize the current status of "Hispanic patients' rights," because it is not clear that such an entity yet exists. The purpose of this monograph is to stimulate debate and action within the patients' rights and advocacy movement and within the Hispanic civil rights movement to address the needs of Hispanic mental health clients.

This article outlines several assumptions about Hispanics that continue to dominate the mental health research, training and service delivery systems, and the author discusses how such a perspective influences patients' rights and advocacy.

Social Assumptions Impacting the Patients' Rights of Hispanics

In discussing the topic of patients' rights and advocacy with mental health advocates, service providers and researchers, the IDRA Mental Health Research Project staff has encountered a number of key assumptions that need to be outlined and analyzed. These assumptions, which are currently held by many individuals interested in the advancement of patients' rights, limit the potential for exploring and developing Hispanic issues of The assumptions coalesce into an interpretation of Hispanic culture as deficient and of Hispanic families and individuals as disadvantaged. The interpretation tends to focus on the psychological characteristics or emotional problems of Hispanics, while ignoring the social environment that surrounds them, and, indeed, it is based on an ignorance of this country's history with respect to Hispanic peoples. The assumptions encompass at least five areas.

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First, because the concept of patients' rights is a relatively new one and its progress is still so rudimentary, racial and/or ethnic issues are sometimes viewed by mental health advocates as superfluous -- the unique aspects of minority mental health clients' situations will have to wait until legal precedents are established and clarified for the field in general. The contention is that minority individuals in a mental health treatment setting generally find their rights far more seriously threatened by their status as an institutionalized or committed patient than by their status as members of a minority group.

Second, as mental health service providers begin to contemplate the situation of Hispanic clients, many identify language as the primary factor of concern. They focus on the communication difficulties that Hispanics often have when attempting to interact with mental health service delivery systems, and the providers frequently conclude that such clients have a "language handicap." There is a tendency to compare them to other physically handicapped individuals, including aphasics, the deaf or retarded persons of limited communication abilities.

Third, because of the predictable diagnosis of language problems, service providers concerned with Hispanic clients' needs may tend to define the major issue as that of due process: informed consent and/or to and screening admittance experimentation or therapy in the face of such linguistic They express comfort in their assumption that these areas are already fairly rigorously controlled (legally, if not in practice), and they recommend that the use of intake interpreters, materials written in Spanish or Spanish-speaking staff will eliminate any serious infringement of the patients' rights of Hispanics.

There is a proclivity to deemphasize or ignore the right-totreatment issue as a major factor, both because the implications of right-to-treatment decisions with respect to the content or substance of therapy is still undergoing vigorous debate and also



because providers may tend to oversimplify the cultural aspects of therapy by their emphasis on language (i.e., "right to treatment is not an important issue since meaningful therapeutic interventions need not be verbal in order to be effective").

Fourth, because of the emphasis on the "linguistic handicip" of Hispanics, mental health service providers do not focus sufficiently on cultural issues relevant to effective therapeutic interventions. There is a distinctive approach, however, which tends to emphasize cultural "exotica" -- such as therapists and researchers who are obsessed with <u>curanderismo</u> and <u>espiritualismo</u> or program staff who decorate clinics with Precolumbian motifs and Mexican curios presumably to create a comfortable milieu for Hispanics in the United States. The dynamic factors of bilingualism, biculturalism, bicognitive processes and other elements inherent to acculturation are either ignored or oversimplified.

Fifth, the most fundamentally damaging assumption, however, is that of homogeneity, in that too many mental health service deliverers, planners, administrators and researchers continue to perceive Hispanics in monolithic terms. The image of a poor, Spanish-speaking immigrant with a rural Indian-based culture is, of course, accurate for segments of the Hispanic population. But ignores the enormous diversity and complex combinations of characteristics found in many other segments; for example:

- <u>language background and use</u>: Spanish monolinguals, Spanish dominants, fluent Spanish/English bilinguals, English dominants, and English monolinguals -- not to mention the fact that fluency in either language does not necessarily imply literacy;
- race: Native American/Indigenous, European descent, Black and all possible permutations due to intermarriage among the racial groups;



- ethnicity: Mexican, Puerto Rican, Cuban, other Caribbean peoples, Central and South Americans, Spanish;
- demographic variability: the Mexican American and Puerto Rican populations are considerably younger and more socioeconomically disadvantaged than other Hispanics;
- immigration experience: Mexican Americans who have been in the Southwestern United States longer than most Anglos, Puerto Ricans and Caribbean peoples who continue to travel between the U.S. and their islands of origin, and Latin American political refugees, as well as the recently arrived undocumented workers from Mexico and other countries;
- regional differences: due to historical and social factors affecting the group; e.g., the New York City environment of most mainland Puerto Ricans or the Miami of Cubans distinguishes them from other Hispanics as much as do ethnic factors; and Mexican Americans in Los Angeles have a very different experience from residents of the Rio Grande Valley in Texas or from Mexican American communities in the Midwest made up of former migrants or railroad workers; and
- social class: although Hispanics as a group are characterized by low socioeconomic status, including limited educational and employment opportunities, there is, nevertheless, important variability within the population and among ethnic groups.

In essence, mental health and other social service delivery systems overlook the demographic realities of the Hispanic presence in the United States. The relative youth and high fertility of the Hispanic population, its dispersion throughout the country, and the immigration from Latin America are three



major trends likely to continue for the next two decades. What are the implications?

Public health facilities, public schools and youth social service programs will see an increasing number and percentage of Hispanic children and adolescents. Because of the differential Anglo and Hispanic populations composition of the (particularly Mexican Americans), there will be an increasing number of Hispanic men and women moving into the age range of 21 to 40 when the majority of emotional and mental disturbances surface (Ramirez, 1981). One could consequently project an increased demand for mental health services by the Hispanic population. Because there have been political and economic gains by Hispanics, continued and accelerated political activity by Hispanic groups and organizations seems probable, and the mental health arena is sure to be impacted.

Future Issues tor Hispanic Mental Health Patients' Rights

There are, of course, different assumptions that can be made about the situation of Hispanic mental health clients. In contrast to an oversimplified characterization of Hispanics as a handicapped population (linguicically, experientially or economically), an alternative interpretation focuses on the interaction between the Hispanic individual or family and the society in which they are attempting to participate. All Hispanics are limited by a national history of oppression and discrimination, as well as an on-going social fear of cultural and linguistic diversity prevalent in the United States. If some Hispanics are "handicapped," or limited, it is frequently due to the colonialist nature of our society and the fact that some regions continue to manifest greater disparity among groups due to that nature (e.g., the Southwest, Puerto Rico, etc.).



Nevertheless, any tendency to polarize mental health theory into a solely colonialist interpretation is as simplistic as one which emphasizes genetic influences as the single cause of mental The subordinate status of Hispanics as a group is a illness. source of considerable stress and self-deprecating attitudes among them. Yet it is also unquestionable that Hispanics, like other populations, are subject to psychiatric disturbances which have genetic or chemical foundations and personality disorders which arise from familial and social interactions. The impact of their history, however, is generally the base upon which emerge destructive effects of these other psychological emotional problems. This interaction of the debilitating impact of a colonialist society and of psychic trauma compounds the severity of Hispanics' problems, creating particularly complex issues for mental health programs and professionals who seek to intervene and resolve or prevent such human suffering.

Yet when Hispanics face the need to seek out mental health encounter resourceful do not they often appropriately complex programmatic responses. Instead, they are confronted with deficient institutions -- institutions which exist in and are funded by a highly diverse multicultural society but which are designed to communicate with and to serve an middle-class clientele. The Anglo English-speaking, administrators and personnel often seem to be oblivious to the history and the socioeconomic reality of the communities in which As has been pointed out by the IDRA Mental Health Research Project, the characteristics of these institutions are essentially incompatible with those of many Hispanics (Ramirez, 1980; Sepulveda-Hassell, 1981). Common sense, as well as organizational theory, would prescribe that the institutions and their staff expand their competencies in order to adapt to the characteristics of their Hispanic clientele.



Demands for institutional change by Hispanics and their advocates in the future will probably concentrate on the personal characteristics of mental health system policy makers, advisers, administrators and service providers. Concerns about due process, the right to information about the treatment process and the right to effective treatment programs will ultimately focus the attention of advocates for Hispanic mental health patients on the individuals running the service delivery system: Who is allocating funds for mental health and substance abuse? Who are the people making decisions about therapeutic and prevention strategies? Who are the individuals implementing and evaluating those strategies? Who are the professors and trainers educating our mental health professionals?

Thus, the identification, recruitment, retention and promotion of Hispanic staff and board members in mental health agencies will undoubtedly be one of the major advocacy issues in the 1980s. Experience by advocates within the educational and criminal justice systems has demonstrated conclusively that until Hispanics are represented at all levels of implementation, there can be no effective system-wide institutional change on behalf of Hispanic clients or consumers. In order to foster innovations in treatment, prevention strategies and community outreach efforts, Hispanics must be present in the system to encourage and evaluate such changes.

Therefore, advocacy on behalf of Hispanic mental health clients will have to occur within the context of two currents, those of the patients' rights movement and the Hispanic civil lights movement. The patients' rights and advocacy movement will have to recognize the urgent necessity of incorporating racial/ethnic and linguistic factors into its concerns. And Hispanic civil rights organizations must accept an additional responsibility of demanding accountability from mental health and substance abuse research programs and service delivery systems.



We are faced with a new social attitude in the 1980s that is attempting to limit the responsibilities of the federal government with respect to minorities and the poor. We are also faced with less economic resources at all levels of government. This means that such advocacy efforts will require renewed dedication and invigorated creativity. It promises to be a challenge encompassing both excitement and constructive conflict, as the two movements seek to make patients' rights and advocacy a multicultural concept.



NOTE

1"Colonialism" is a concept which is sometimes difficult for citizens of the United States to accept as applicable to their society. M. Barrera in Race and class in the Southwest: A theory of racial inequality (Notre Dame: University of Notre Dame Press, 1979) presents an economic history or Mexican Americans or Chicanos and analyses internal colonial theory, examining both structural discrimination and class segmentation in the southwestern U.S. Barrera defines colonialism as:

... a structured relationship of domination and subordination, where the dominant and subordinate groups are defined along ethnic and/or racial lines, and where the relationship is established and maintained to serve the interests of all or part of the dominant group. (Barrera, 1979, p. 193)

He defines internal colonialism as a form of colonialism where:

the dominant and subordinate populations are intermingled, so that there is no geographically distinct "metropolis" separate from the "colony." (Barrera, 1979, p. 194).

barrera contributes a synthesis of internal colonial and class segmentation theories to demonstrate that Chicanos occupy a subordinate structural position at all class levels.

See R. Acuña, Occupied America: The Chicano's struggle toward liberation (San Francisco: Canfield Press, 1972) for an earlier outline of the thesis that Chicanos are a colonized people. E. Murguia in Assimilation, colonialism and the Mexican American People (Austin: Center for Mexican American Studies, The University of Texas at Austin, 1975) contrasts the two conceptual models of assimilation and colonalism with respect to



the Mexican American experience in the U.S. He discusses the decolonialization movement and concludes that a cultural pluralism model may emerge. W. Moquin and C. Van Doren (Eds.) A documentary history of the Mexican Americans (New York: Praeger, 1971) provide original sources which support the contention that Mexican Americans became "an exploited minority relegated to second-class citizenship in their own homeland." 0

For a community case study of race relations and socioeconomic factors relating to contemporary Chicano politics, see D. Foley, C. Mota, D. E. Post and I. Lozano, From peones to politicos: Ethnic relations in a South Texas town 1900-1977 (Austin: Center for Mexican American Studies, The University of Texas at Austin, 1977). S. J. Andrade in Chicano mental health: The case of Cristal (Austin: Hogg Foundation for Mental Health, 1978) offers another case study of a South Texas town's attempt to develop a rural mental health program in a highly politicized. Chicano community which revolted against its colonized status.

A. Fortes and R. L. Bach, in their article "Immigrant earnings" (International Migration Review, 1980, 14, 315-341) report an investigation of the incomes of Mexican and Cuban male legal migrants. The authors discuss the realities of the dual labor market which confronts these men as they try to find jobs and to earn a living for their families. Portes and Bach conclude that many such Hispanics are trapped in a secondary labor market, in which they are not hired according to their skills but rather according to their ethnicity. Hispanic men's jobs are characterized by a general instability, and they receive lower wages in spite of their skills, status, education or aspirations.

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Puerto Ricans in the new economic order" by F. Bonilla and R. Campos (<u>Daedalus</u>, 1981, <u>110</u>, 133-176); and "La carreta made a Uturn: Puerto Rican language and culture in the United States" (<u>Daedalus</u>, 1981, <u>110</u>, 193-217).



APPENDICES



APPENDIX A

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¹Federal court decisions can be identified as those of the Supreme Court, which include the abbreviation U.S. in their citation, e.g., In re Winship, 397 U.S. 358 (1970), or of the federal district courts, which are identified by their number in parentheses, e.g., Jacoson v. Bishop, 404 F 2d 571 (8th Cir. 1968).

State court decisions are denoted by reference to the state in parentheses, e.g., <u>Lessard v. Schmidt</u>, 349 F. Supp. 1078 (E.D. Wis. 1972).

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